

Participant Information Sheet/Consent Form

The University of Melbourne

Title	Supportive Strides: Co-designing Community-Based Walking Programs with embedded Peer Support for People after Stroke
Short Title	Supportive Strides Co-design
Project Number	32829
Investigator (s)	Dr Natalie Fini Ms Priyanka Cahill Dr David Gallant A/Prof Iderlina Mateo-Babiano Dr Andrew Martel Ms Louise Suttie Mr Brian A. Beh A/Prof Claudia Marck A/Prof Kate Hayward Dr Emily Ramage
Coordinating/Principal Investigator (CPI)	Dr Natalie Fini Natalie.fini@unimelb.edu.au
Location	The University of Melbourne

Part 1 What does my participation involve?

1 Introduction

This **Participant Information Sheet** tells you about the research project. It explains what is involved and can help you decide whether or not you would like to participate.

Please take time to read this information carefully. Please ask **questions** about anything you don't understand or want to know more about.

Your participation is **voluntary**. If you don't want to take part, you don't have to. If you are participating, you can **withdraw** at any time

If you decide you want to take part in the research project, you will be asked to sign the consent form. By signing it you are telling us that you:



If you decide you want to take part in the research project, you will be asked to sign the consent form.

By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and the Consent Form to keep

2 What is the research about?

Many people are physically active before having a stroke. It's important that there are systems in place to help stroke survivors stay active. A program that is easy to access and offers peer support could help stroke survivors reconnect with who they were before having a stroke, become active and regain their sense of identity.

The aim of this project is to work with stroke survivors, carers, health care workers, urban designers, policy makers and people from professional and community organisations to develop a community-based walking program for stroke survivors. This program is called Supportive Strides.

This research has been initiated by the researcher, Dr Natalie Fini and funded by the Melbourne Disability Institute

3 What do I have to do?

You will be asked to participate in 1 or 2 workshops (like a group meeting) to share ideas about designing a successful walking program for stroke survivors. You will be

invited to discuss a range of questions about potential key elements of a community walking program for people after stroke.

Workshops, Phase A At this first workshop, you will be supported to discuss your knowledge, opinion and experiences to guide the development of a walking program called 'Supportive Strides' for people after stroke. This workshop will take up to 2 hours. There will be an opportunity to attend either an in-person workshop at the University of Melbourne or Virtual Workshop via Zoom. We anticipate there will be three separate workshops with 6-8 people in each one. If you are unable to attend one of the workshops you may be offered the opportunity to complete a one-on one interview. The total number of participants across virtual and in-person workshops will be between 20 and 30.

Workshops Phase B- In this workshop you will be shown the Supportive Strides program and any associated resources that have been designed. You will then be able to discuss what **you think about it and ways to make it better**. All previously recruited participants from Phase A workshops are invited to come back for the second workshop. Some new participants may also be recruited. There will be an opportunity to attend either an in-person workshop at the University of Melbourne or Virtual Workshop via Zoom. We anticipate there will be three separate workshops with 5-8 people in each one. If you are unable to attend one of the workshops you may be offered the opportunity to complete a one-on one interview. The total number of participants across virtual and in person workshops will be between 15 and 25.

About the Workshops

The workshops will be **in person** at University of Melbourne

OR



via **videoconference** or **phone call**.



The workshops will be audio and/or video recorded so that the researchers can review the information discussed. The researchers will also take notes during the workshop

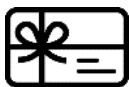


In the workshops you will have the opportunity to interact with the researchers and other people participating in the project. This could include stroke survivors, carers of stroke survivors, health professionals, urban designers, policy makers and people from community and professional organisations.



Within 2 weeks of your interview, we will provide you with a **written summary of the interview** (via email or post).

4 Other information about the research project



There are **no costs** associated with participating in this research project. You will be given an \$80 gift voucher to thank you for your time. We will pay for travel costs for in-person workshops such as parking or taxis as required.

5 Do I have to take part in this research project?

- Participation in any research project is **voluntary**.
- If you do not wish to take part, you **do not have to**.
- If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.
- If you decide to take part and then change your mind, you can **withdraw** from the project **at any stage**

- Your decision **will not affect** any routine treatment you are having from any hospitals or health services.

6 What are the possible benefits of taking part?

You may not directly benefit from participation in this research project, but this work may help others who have had a stroke or have a stroke in the future.



We are trying to develop a walking program called Supportive Strides that supports stroke survivors to engage in a regular physical activity walking program that embeds peer support and socialisation.

7 What are the possible risks of taking part?

There are very few risks. There is a small chance you may become uncomfortable talking about your experiences. We will support you if this happens. You don't have to talk about anything you do not want to. Our experienced research team will provide you with support if this occurs and a chance to correct what was said. You can leave the workshop if you wish.

If you feel upset you can contact:

- the Principal Investigator,
- Your GP, and/or
- Beyond Blue (available 24 hours a day) on 1300 224 636 or at <https://www.beyondblue.org.au/>

You may get tired in the workshop, please let the research team know if this is the case. We will provide regular breaks during the workshops.

8 What if I withdraw from this research project?

If you decide to withdraw from the project, please **tell** a member of the research team **before** you withdraw.

If you do withdraw your consent during the research project, the research team **will not** collect extra personal information from you, although personal information **already collected** will be **kept** to ensure that the results of the research project:

- can be measured properly
- comply with law.

Data collected by the research team up to the time you withdraw will be part of the research project results.

If you **do not** want the research team to do this, you **must** tell them before you join the research project.

9 Could this research project be stopped unexpectedly?

Although it is unlikely, if this project is stopped before it is finished, we will tell you.

10 What happens when the research project ends?

At the end of the whole project, you will be offered a one-page summary of the findings.

You will be given the opportunity to see the program once it has been developed.

11 What will happen to information about me?

Your personal information and all data including questionnaires, audio recordings and the notes from the workshops will be kept by the University of Melbourne. Data will be stored on a password-protected file or in a secure filing cabinet. It will only be accessed by the researchers named on this document. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission,

except as required by law. All data will be held for 5 years after the last report is published. After this time, the data will be destroyed to ensure your confidentiality is maintained.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team within 5 years. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

The results of this study may be published and/or presented in a variety of forums. In any publication and/or presentation, information will be presented so that you cannot be identified, except if you have given the researchers written permission to be identified.

12 Where can I get further information?

If you suffer any injuries or complications as a result of this research project, you should **contact** the research team as soon as possible. You will be assisted with arranging appropriate medical treatment.

Name	Dr Natalie Fini
Position	Physiotherapist / Principal Researcher
Telephone	0401 303 749
Email	natalie.fini@unimelb.edu.au

13 Who is organising and funding the research?

This research project is being led by Dr Natalie Fini

This research project is being funded by the Melbourne Disability Institute.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the University of Melbourne

15 Further information and who to contact

If you:

- want any further information about this project OR
- have any medical problems which may be related to your involvement in the project (for example, any side effects).

You can contact the principal researcher.

Coordinating Principal Researcher (CPI):

Name	Dr Natalie Fini
Position	Physiotherapist / Principal Researcher
Telephone	0401 303 749
Email	natalie.fini@unimelb.edu.au

For matters relating to research or if you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact person

Position	Research Integrity Administrator, Office of Research Ethics and Integrity
Telephone	(03) 8344 1376
Email	Research-integrity@unimelb.edu.au

All complaints will be treated confidentially. In any correspondence please provide the name of the research team and/or the name or ethics ID number of the research project.



Consent Form - *Adult providing own consent*

Title Supportive Strides: Co-designing Community-Based Walking Programs with embedded Peer Support for People after Stroke

Short Title *Supportive Strides*

Project Number 32829

Coordinating Principal Investigator (CPI) Dr Natalie Fini

Site Principal Investigator (PI) Dr Natalie Fini

Location The University of Melbourne

Consent Agreement

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I understand that any workshops or interviews I participate in will be audio and/or video recorded.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the study.

I understand that I will be given a signed copy of this document to keep.

Declaration by Participant – for participants who have read the information

Name of Participant (please print) _____

Signature _____ Date _____



Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher† (please print)	

Signature	Date
_____	_____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.



Form for Withdrawal of Participation - *Adult providing own consent*

Title Co-designing

Short Title Supportive Strides Co-design

Project Number 32829

Coordinating Principal Investigator (CPI) Dr Natalie Fini

Site Principal Investigator (PI) Dr Natalie Fini

Location The University of Melbourne

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me

Name of Participant (please print) _____
Signature _____ Date _____

Circumstances:

Declaration by Study Doctor/Senior Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher [†] (please print) _____
Signature _____ Date _____

[†] A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.